

THE DESIGN AND IMPLEMENTATION OF A STATEWIDE PERINATAL AUTOMATED MEDICAL NETWORK FOR MICHIGAN (PAM/NET)

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ABSTRACT

PAM/NET is a multi-institutional computer based Neonatal research data base and conferencing system using a large university based mainframe computer (Amdahl 470/V8). The data base functions are provided by a sophisticated inverted file relational data base management system (MICRO) developed by the Institute for Labor and Industrial Relations. The conferencing system (Confer) supports open continuing discussions, bulletins, and private messaging. The design of the PAM/NET system was specifically tailored to encourage and foster sharing data between institutions, while supporting their needs for confidentiality and data security.

BACKGROUND

The system's development began in 1978 when the Neonatology unit at the Children's Hospital of Michigan instituted a computerized Neonatal data base. This data base consisted of clinical summary information which covered demographics, prenatal conditions, intrapartum conditions, birth information, diagnoses, treatments, complications, and immediate outcome.¹ In addition, a program was devised to generate a summary report for each case which appeared to be a narrative summary of the hospital course of the infant in the form of a letter to the referring physician.²

In 1982, the State of Michigan Department of Mental Health sought resources for a perinatal data base system which would aid statewide studies in perinatal outcome, and facilitate tracking high-risk newborn infants through their medical follow-up process in Developmental Assessment programs (DAC's).

The Perinatal Association of Michigan (PAM) was selected and provided funding to develop such a system. The Neonatology Unit and the Computer and Informatics Research Division of the Children's Hospital of Michigan were jointly appointed by PAM to develop the software, training materials, and plans for implementation and distribution of the system. The following is a description of the project and our progress to get all of the tertiary care Neonatal units (Level III) and their associated Developmental Assessment Clinics into a common data storage and

retrieval network to facilitate the ultimate pooling of important clinical and community health information.

SYSTEM DESCRIPTION

The PAM/NET system resides on a computer (Amdahl 470/V8) that is connected to the MERIT Network. This is a network of university computers in Michigan. MERIT sites are located at five Michigan universities. In addition, the MERIT network maintains connections to the Telenet and Automet national networks and to Datapac, the Canadian counterpart. Thus access to the PAM/NET System is easily available to most users via standard telephone lines without long distance calls. The system is divided into PAMTALK and PAMDATA.

Database System

PAMDATA is the data storage and retrieval system. It is implemented through a relational data base management system (Micro) providing four basic data types, each with several subtypes or definable characteristics. Character type variables may be defined to be a fixed length up to 256. Numeric variables may be defined as integers, or as real numbers using scaling to define the number of decimal places. Numeric variables at definition are assigned a length of 1 to 4 four bytes and may be signed or unsigned. Categorical variables are stored as integer numbers which correspond to labels (11 character), abbreviations (4 characters), and descriptions (256 characters) stored in the data dictionary. The integer value, label, or abbreviation may be used at data entry or output at the user's convenience. External variables are stored pointers to lines of an external character file. The pointers require only 4 bytes of fixed storage, while the character data stored in the external file uses a variable length record up to 32000. This efficiently permits storage of narrative information about the patient in as much as no large fixed space is necessarily reserved. This is a desirable characteristic especially when such data is not necessary for all records.

The perinatal data is stored in five separate relational sets. Though any member institution may have additional sets defined for their specific needs. AUMDATA is the set of information

available to the clinicians when an infant is admitted to the special care unit. DISCHDATA is the remaining clinical information that is gathered during the hospital stay and is derived from the infant's medical record at discharge. The third data set was developed for the storage of demographic, social, and clinical information collected in the follow-up Developmental Assessment Clinic (DACDATA). These three patient records are related through a common medical record number. In addition, each institution stores a data set with names and addresses of referring physicians and signature blank data for their own medical staff. Relational keys to these sets are stored in the clinical sets so that these pieces may be added automatically to reports and letters generated by the system. Data forms are used to facilitate collection of the data from the medical records (figures 1 & 2).

Data retrieval is available on the system in at least three forms. The first form of data retrieval is provided by the query language offered by the data base management system. This query language supports many relational operations (e.g. join and combine). It also provides subset formation with selection criteria using a SQL type of language (e.g. FIND IN ADMDATA WHERE BIRTHWEIGHT < 1250 AND SEX IS MALE --or-- FIND IN DISCHDATA WHERE DATE.OF.DISCHARGE IS FROM 840101 TO 841231). With the query language, new fields can be computed from existing data and simple statistics may be reported (e.g. mean, minimum, maximum, count, variance, and crosstabulation). The query command language also contains several options for outputting the data in tabular format.

Secondly, there are formatted narrative summaries that can be generated on admission from the data contained in ADMDATA, on discharge from ADMDATA and DISCHDATA, or after a DAC visit from all three clinical data sets. These summaries take data from the relevant sets to produce a narrative summary (figure 3). In the summary, the patient is referred to using his/her name or appropriate pronoun depending on the value of the sex field in the ADMDATA set. Similarly, decision trees are used throughout the summary production to change the syntax and content depending on the value of data elements in the record. This is accomplished with a symbolic language developed by one of us (GEC) which facilitates easy composition of complex data sensitive narrative output of record field values (figure 4).

The third form of data retrieval depends on the database management system's ability to perform a predefined series of commands (macro language) with variable passing at execution. Standard reports may be "programmed" in this language for later execution with a simple macro command.

Data entry and the altering of data are facilitated in an interactive way by the data base management system. The system contains shortcuts to manual data entry by providing user defined

default values and type-ahead entry. Transaction file processing subroutines permit batch data entry or editing. This makes possible off-line microcomputer based data entry mechanisms.

The issue of confidentiality and security was important to the institutions participating in this project. The issue was handled by having the data for each institution stored in computer files that are their own. No individual can access the data files without a four character sign on identifier assigned by the project director, a password (up to 12 characters) set locally, and proper file access permission status set by the institution representative. Since common data dictionaries are used, data sharing is easily accomplished. Subsets of the data (excluding personal identifiers) may be selected and made available to other institutions.

Conferencing

PAMTALK is a computer based conferencing system using the Confer program developed by Advertel Corporation (Ann Arbor, MI)³. Each person using the system becomes a member of the conference. The conferencing program permits three types of communications. 1) Continuing open discussions can be initiated by any member. Responses to open discussion are chained as other members add to the discussion in progress.

Members may view any entire discussion item or only those responses not yet seen. There may be any number of simultaneous ongoing discussion items, each with their chain of responses. The discussion items are organized post-hoc with an agenda that allows members to find items according to topic. Agenda categories are created by the conference director as needed. A discussion item may be indexed under several agenda topic categories. 2) Bulletins are paragraphs of information which may be posted by any member. Other participants may not respond to bulletins. At the time of posting, the bulletin is given an effective date upon which it will appear and an ending date, after which it will be automatically removed. At each entry into the conference, a member is automatically presented with any bulletin not yet seen. 3) Messages are private communications between members. These conversations are composed of chains of alternating responses, but viewing is restricted by naming participants as is customary in electronic mail. The conference has proven very useful to announce new features of the network, gather opinions proposed about modifications to the system, and continue the training process for users long after the initial training sessions are completed.

STATUS REPORT

Once the system was designed, a detailed user's manual was written and checked by novices for clarity. We invited individuals from five pilot sites into our institution for an all-day orientation which included an overview of the system

and practice with each of its parts using practice data sets.

This workshop was received enthusiastically, but only one of the pilot sites actually continued with little trouble to use the system after the workshop. That one site was the only one that had equipment in place upon returning home. All of the others had ordered equipment (\$2000--6000), but had not received it. For these four institutions, the enthusiasm and knowledge gathered at the workshop soon faded. Three of them had some equipment problems when they were able to implement the system locally that discouraged them easily because they had trouble differentiating hardware problems from problems with the software or their understanding of it. While these problems were resolved, it required a visit to their site to do so.

Hardware problems encountered in the initial implementation phase included a new printer that was malfunctioning, the use of a telephone line that featured a second-caller signal that periodically interjected noise, microcomputers delivered without the necessary accessories for communication, and very delayed ordering or delivery. Since this experience, we have insisted that new institutions joining the system purchase and test their equipment in advance, and that all training be done at their institution on the equipment which will be routinely used. Most start-up problems have been eliminated by this simple prerequisite. Furthermore, we have found that successful implementation was especially enhanced by having one person at the institution dedicated to the task of using the PAM/NET system and only much later bringing others in. Too early distribution of responsibility for system use within an institution slows the development of the local resource person. Once the local resource person has gained some facility in using the basic parts of the system, including the conference, that individual finds a host of creative ways to use the system to serve the local needs. He/she then begins to teach others to use the system with enthusiasm and conviction of the utility of the system.

Now that the pilot project is completed, three of the pilot sites have taken over the cost of keeping it running for their institutions. In addition to these, and the home site at CHM, three additional sites in Michigan and one in Illinois have also joined the system. Of the two pilot sites which chose not to continue, one never was able to acquire adequate hardware, through misunderstandings and lack of administrative follow through. The other had a long delay between training and obtaining the hardware, lost what enthusiasm they had, and were very frustrated in relearning the system. They gave up very early in the piloting. At the onset of the project, it was felt that the referral letter writing routines would help justify the cost of data entry and system maintenance. The results have been mixed. Three of the current users are making extensive use of the letters, one some, and the other four sites do not use this feature.

All of the sites find that the access to the clinical and demographic data justify the money and effort. Some multi-institutional studies have already been suggested. At least one research project has been submitted for publication based on data collected and analysed via the system.⁵

FUTURE PLANS

Currently expansion of the system has not proceeded as was expected. This may be due in large part to the absence of governmental funding that was expected. It is believed that several institutions which have expressed interest in joining have delayed the decision waiting to see if State funding will be extended. The current cost for computer time for a typical site is about \$4000 per year. Thus the 18 level III hospitals in Michigan could be supported for under \$75,000 per year. Present development of the system is centered about designing a microcomputer based component for the system which will distribute some of the data entry and editing functions. This will increase the initial cost (purchase of a microcomputer rather than simply a terminal), but reduce the ongoing cost. Further incentives to join the system are expected to come from the sponsoring organization, the Perinatal Association of Michigan. We hope to have all eighteen level III perinatal centers in Michigan enrolled in PAM/NET in the coming year.

REFERENCES:

1. Poland, RL, Bollinger, RO, and Cummings, GE: A statewide Perinatal Automated Medical Network for Michigan (PAM/NET). Perinatology-Neonatology (in press), 1985.
2. Poland, RL and Cummings, GE: Computer generated neonatal discharge summary letter. In Harris, T and Bahr, J. The use of computers in perinatal medicine. Praeger, NY, 1982, pp. 213-217.
3. Kahn, MA, Rumelhart, DL, and Bronson, BL: MICRO Information Management System. Institute for Labor and Industrial Relations, Ann Arbor, 1977.
4. Parnes, R: Beginner's guide to Confer. Advertel Corp., Ann Arbor, 1982.
5. Poland, RL, Bollinger, RO, Bedard, MP, and Cohen, SN: An Analysis of the Effects of Applying Federal DRG Guidelines to a Population of Highrisk Newborn Infants. Pediatrics 76:104-109, 1985.

ADMPATA

Sentences to be completed: (If you add a subsequent sentence, place punctuation in middle, but not at the end)

PAST.MED.HIST*(PWR) Prior to admission to our NICU, he/she

ADM.PHY3-(PE-) The physical examination on admission revealed "

PROBLEM.LIST=(LST=) His/her problem list on admission includes '

ACMIT.STATUS*(STAR) His/her condition at this time is *

Side 1

DISCHDATA

Sentences to be completed: (If you add a subsequent sentence, place punctuation in the middle, but not at the end)

XRAY=(XRAY) X-ray examination

ADM LAB VALUES (LAB#) Pertinent laboratory values obtained during this admission included:

EX.DISCN=(DIS=) He/She was discharged on (date) at (x) days of age on "

(diet and medications only. Date and age are filled in automatically)

REF. PRCS3=(PRG=) His/Her problems at discharge were :

(stable? resolved?)

FOLLOWUP=(FUP=) - complete A or B

A) Discharge: He/She will be seen for follow-up by

8) Transfer: Continued in-patient care will be provided by the

OX.DISCN=OXN) Discharges at discharge were

Slide 1 (all diagnoses except SEX, GESTATIONAL AGE, GA CATEGORY)

Abstract The purpose of this study was to determine the effect of a 12-week, low-intensity, supervised walking program on the physical and psychological health of sedentary, middle-aged women. The study was a randomized, controlled trial. The subjects were 40 sedentary, middle-aged women who were randomly assigned to either a supervised walking program or a control group. The walking program consisted of 12 weeks of supervised walking, 3 times per week, for 30 minutes per session. The control group consisted of 20 women who did not participate in the walking program. The subjects were assessed at baseline and at 12 weeks. The walking program had a significant positive effect on the physical and psychological health of the subjects. The walking program significantly improved the subjects' physical health, as measured by the 6-minute walk test, and their psychological health, as measured by the Beck Depression Inventory and the State-Trait Anxiety Inventory. The walking program also significantly improved the subjects' quality of life, as measured by the SF-36. The walking program was well tolerated and had no adverse effects. The results of this study suggest that a 12-week, low-intensity, supervised walking program can improve the physical and psychological health of sedentary, middle-aged women.

2000

1.00 OTHERS (1.00%):

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PROC.OTHER= (PRO):
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RX.OTHER[®] (RXID[®]); *

BY OTHERS (ONLY): _____

— 0.76 —

Side 2

Figure 1. Admission data form.

Figure 2. Discharge data form.

RECORD# 870011
 SURNAME Cameron
 FIRST NAME
 MOTHERS NAME Carol
 ADDR.PHONE* 1111 Lion, Detroit, Michigan, 555-8888
 ZIPCODE 48288
 HOSPITAL* Sharp Memorial Hospital
 REF.PHYS* Smith
 ATT. INITIALS mba
 BIRTHDATE 850127
 ADMITDATE 850127
 SEX MALE
 RACE BLACK
 BIRTHWT 1985
 HEAD.CIRC 30.5
 LENGTH 45.0
 ADM.WT 1990
 GEST.AGE 35
 C.A. CATEGORY AGA
 NO. BIRTHS SINGLE
 TWIN.A.B FIRST
 APCAR1 7
 APCAR5 8
 MATAGE 36
 MARITAL MARRIED
 GRAVIDA 3
 PARITY 2
 ABORTUS 1
 CHIEF.COMPL PREM.RDS
 PREMAT.DX1 NO.CARE
 PREMAT.DX2 NOT.STATED
 PREMAT.DX3 NOT.STATED
 INTRAPARTUM1 PROM24
 INTRAPARTUM2 BRECH
 INTRAPARTUM3 CAESARIAN

March 5, 1985

Frank Smith, M.D.
 Sharp Memorial Hospital
 1620 Louis St.
 Detroit, Michigan 48220

Re: Baby Boy Cameron
 (Hospital Record #999011)

Dear Doctor Smith:

Baby Boy Cameron was born on 01/27/85 at Sharp Memorial Hospital and transferred to our NICU on the same day because of prematurity and respiratory distress.

He was born after a 35 week gestation, to a 36 year old, gravida 3, para 2, married woman. The pregnancy was complicated by a lack of prenatal care. Delivery occurred under spinal anesthesia. Events of the intrapartum period included premature rupture of membranes (>24 hr.), breech presentation, and cesarean section. His birthweight was 1985 grams. His Apgar scores were 7 at 1 minute and 8 at 5 minutes.

Prior to transfer to our Neonatal Unit, he had increasing respiratory distress. Infant was meconium stained at birth. After blood cultures were done, antibiotics were initiated. The baby was intubated by the CBN transport team.

At the time of admission to our Neonatal Unit, his weight was 1990 grams. His head circumference was 30.5 cm. His length was 45.0 cm. The physical exam revealed a pink intubated baby with moderate respiratory distress. The X-ray examination of the chest showed hyaline membrane disease. Echoencephalogram showed minimal caudate hemorrhages. Pertinent laboratory values obtained during this admission included negative blood and CSF cultures. The highest serum bilirubin concentration was 15.9 mg/dl.

He received the drugs gentamicin, ampicillin, and cephalosporin. He was transfused with packed cells. Other treatments administered were phototherapy and mechanical ventilation. He required assisted ventilation for 6 days.

Baby Boy Cameron
 (Record #999011)
 03/05/85 - continued

He was discharged on 02/06/85 at 10 days of age on 20 calorie formula. At the time of discharge, his weight was 1990 grams, head circumference was 30.5 cm, and length was 45.0 cm. The last hematocrit obtained was 57.8% and the last reticulocyte count was 6.6%. His problems at discharge were resolved. A routine eye examination will be scheduled as an outpatient. He will be seen for follow-up by their family physician and Eye Clinic.

Diagnoses at discharge were a preterm male infant, 35 weeks, appropriate weight for gestational age, with hyaline membrane disease, hyperbilirubinemia, caudate hemorrhage.

Procedures done during this hospitalization included circumcision, echoencephalography, and a complete workup for sepsis.

Thank you very much for the referral of this patient. If you have any questions, or if I may be of any further assistance, please do not hesitate to call me at (313)494-5640.

Sincerely,

Mary B. Steward, M. D.
 Associate in Neonatal-Perinatal Medicine,
 Children's Hospital of Michigan
 Associate Professor of Pediatrics,
 Wayne State University

MPS/rob

cc: Head Nurse, N B Nursery
 Sharp Memorial Hospital
 Dr. Small

Figure 3a. Portion of admission record.

RECORD# 870011
 PEAK.BILI 15.9
 XRAT* of the chest showed hyaline membrane disease.
 Echoencephalogram showed minimal caudate hemorrhages
 ABN.LAB.VAL\$* negative blood and CSF cultures
 EX.DISC# 20 calorie formula
 REM.PROBS* resolved. A routine eye examination will be scheduled as an outpatient
 FOLLOWUP* by their family physician and Eye Clinic
 DX.DISC# hyaline membrane disease, hyperbilirubinemia, caudate hemorrhage
 LAB.ABNORM1 BILIRUBIN
 LAB.ABNORM2 NONE.NOTED
 LAB.ABNORM3 NONE.NOTED
 LAB.ABNORM4 NONE.NOTED
 SURG.PROCEDURE1 CIRC
 SURG.PROCEDURE2 ECHOENCEPH
 SURG.PROCEDURE3 SEPSIS.WU
 SURG.PROCEDURE4 NOT.STATED
 TRANSFUSION PKD.CELL
 TRANSFUSION2 NONE.NOTED
 TRANSFUSIONS3 NONE.NOTED
 DRUGS.GIVEN GENTAMICIN
 DRUGS.GIVEN2 AMPICILLIN
 DRUGS.GIVEN3 CEPHALOSPOR
 DRUGS.GIVEN4 NOT.STATED
 DRUGS.GIVEN5 NOT.STATED
 RX.WONDURG PHOTO.RX
 RX.WONDURG2 VENTILATOR
 RX.WONDURG3 NOT.STATED
 RX.WONDURG4 NOT.STATED

Figure 3b. Portion of discharge record.

[* BODY OF LETTER]
 [L]
 [L]Baby (FN=NULL)/FN=CAPF/ (FN=NULL)/SEX=DESC/ (I)/NAME=CAPF/ was born (DOB#O) on /DOB#DATE1/
 at /HSP/[I] PLACE OF BIRTH
 (CC=88)[S1](CC=88)[S2](I)
 (FLAG1[FLAG2] and transferred to our NICU
 on (ADM#18ADM#2)/DO#DATE1/ (ADM#1)the same day (ADM#2)the following day (I)because of (FLAG1) /CC#DESC/ (FLAG2) /CC#/(I) [C1][C2]
 [* CHIEF COMPLAINT AS CODED OR IN EXTERNAL FIELD IF OTHER]
 [* *****]
 [* PERINATAL INFORMATION]
 [L]
 [L](FN=NULL)/FN=CAPF/ (FN=NULL)/PRO1#NAME/(I) was born (AGE#M#O)[S1](I) [* MATERNAL AGE GIVEN]
 (GRAV#O)GRAV#99)[S2](I) [* GRAVIDA GIVEN]
 (PARA#99)[S3](I) [* PAROUS GIVEN]
 (FLAG1[FLAG2][FLAG3])[I] [* MATERNAL INFO TO PRINT]
 (B.NO>1), the /MULT#DESC/ of /B.NO#DESC/ (I)
 after a (G.A#O)/G.A/ week gestation.(G.A#O)gestation of unknown length.(I) [* GESTATION to a
 (AGE#18)n(FLAG1) /AGE#/ year old.(I) [* MATERNAL AGE]
 (FLAG2) gravide /GRAV/ (I) [* NUMBER OF PREGNANCIES]
 (FLAG3#PARA#O) para /PARA/ (I) [* NUMBER OF LIVE BIRTHS]
 (FLAG3#PARA#O) nulliparous (I)
 (MART#O)MART#99) /MART#DESC/ (I) [* MARITAL STATUS]
 (FLAG1[FLAG2][FLAG3] woman.(I) [* CLEAR ALL FLAGS][C1][C2][C3]

Figure 4. Letter writing language sample.

Figure 3c. Sample discharge referral letter.